

## Continuity Assessment Tool for Delivery of Pediatric Palliative Care

Date: \_\_\_\_\_ Name/ID for Network/Coalition: \_\_\_\_\_

City: \_\_\_\_\_ County: \_\_\_\_\_ State: \_\_\_\_\_

Zip Code: \_\_\_\_\_

**Relevant Definitions:** For the purpose of this self-assessment, please refer to the following definitions:

- **Networks/coalitions** - are groups of individuals and/or organizations working together (usually within one geographic community) to care for children and families.
- **Systems or Care Systems** - include the people and organizations providing care, the people receiving care and all the processes involved in care delivery.

The **Continuity Assessment Tool** is designed to help emerging care systems determine their stage of development along six tracks. By studying successful care systems, Gems of Care identified key structural and functional elements and stages of development of these systems and then used this information to define six tracks along which most care systems will develop. An evolving care system may be at different stages in each track at the same time. The goal is to move to a more advanced stage on each track over time.

These tracks, and the progression along each one, form the basis of the Gems of Care continuity assessment.

### Six tracks for care system development:

1. <b>Networking and collaboration</b>	Potential partners serve children in the community but are not coordinated	→	Full complement of participating partners
2. <b>Critical elements of a continuity system</b>	A few elements are planned and/or implemented	→	All elements fully implemented
3. <b>Funding</b>	A few services are funded or have a plan for funding	→	Services fully funded via sustainable sources
4. <b>Access</b>	Few patients getting coordinated care	→	All targeted patients getting coordinated care
5. <b>Clinical capacity building</b>	A few education/ mentoring activities exist or are being planned	→	Multiple opportunities for education and support
6. <b>Outreach</b>	Few outreach activities	→	Multiple outreach activities

1. **Networking and collaboration:** Indicate the level at which each of the following entities are currently involved in your evolving pediatric palliative care system

Participating Entities (listed alphabetically)	0	1	2	3	4
	Not envisioned as part of the PPC care network/ coalition	Potential: Serve children/ families in community but not yet part of care network/ coalition	Networking: Just beginning involvement with network/ coalition	Early involvement: Coordinated care with at least one other network/ coalition entity, for at least one patient in the last 6 months	Coordination/ collaboration: Regularly participate with one or more other network/ coalition members in care of pediatric patients and outreach
Bereavement care providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community nursing providers (practicing independently)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community physicians and/or nurse practitioners (practicing independently)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary care providers (practicing independently)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disease-specific organizations - local chapters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early intervention specialists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emergency medical services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Faith communities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family members (using a broad definition of family that includes committed friends)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family services agencies (Government or private)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Governmental agencies for children's medical services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home health agencies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospitals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insurers (Governmental or private)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical education professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other key organizations serving children (e.g., camps)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Schools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vendors (e.g., DME, oxygen, supplies)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. **Critical elements of coordinated care:** Indicate the level of implementation of each of the following critical elements of a pediatric palliative care system

Elements of a pediatric palliative care system	0	1	2	3	4
	Not present and/or not planned	In planning	Early implementation	Mid-implementation	Fully implemented
The care system has defined explicit working relationships (whether contractual or not) for entities participating in care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The care system has defined specific, standard communication mechanisms for providers and families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Each child/family in the care system has a central coordinating entity, available 24/7, that is acknowledged by other providers as being “in charge” of care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The patient has a shared care plan to address patient/family needs and preferences, developed with input from the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care delivery is based on the patient’s shared care plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a formal mechanism to track services delivered to each patient/family served by the system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a standard mechanism to track satisfaction and outcomes for patients/families and providers in the coalition/network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. **Funding:** Indicate the level/source of funding for each of the following services

Services	0	1	2	3	4
	Not being funded and no viable plan is in place	Not being funded but have a viable plan to obtain funding	Funded partially or fully through non-permanent, non-insurance funding	Partially funded through insurance reimbursement, sustainable charitable donations/philanthropy (such as an endowment), or other sustainable source*	Fully funded through insurance reimbursement or sustainable charitable donations/philanthropy (such as an endowment), or other sustainable sources*
Infrastructure/administration of the coalition/network or “care system”	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical salaries (for inpatient and/or outpatient palliative care professionals) - <i>NOTE: Do not count per visit reimbursements as “salary.”</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inpatient physician and/or nurse practitioner visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inpatient nurse visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inpatient social work visits/services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inpatient chaplain visits/services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outpatient/in-home physician and/or nurse practitioner visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outpatient/in-home nurse visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outpatient/in-home social work visits/services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outpatient/in-home chaplain visits/services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary care provider visits/services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Case management/ care coordination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Out-of-hospital infusion services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Supplies, DME, oxygen, etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outreach activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* Examples of other sustainable sources include income from educational programs or product sales; memorials.

4. **Access:** Based on your knowledge or best estimate of the number of children with life-threatening illness in your community who might benefit from coordinated pediatric palliative care services\*, what percentage of them do you think are currently receiving those services?

\* *Coordinated pediatric palliative care services are those that address children/family medical, social, emotional and practical needs over time and across settings.*

0	1	2	3	4
0%	1% to 25%	26% to 50%	51% to 75%	76% to 100%
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. **Clinical capacity building:** Indicate the level of implementation/availability of each of the following for building capacity to deliver PPC in your community, whether provided through your network/coalition or another source.

	0	1	2	3	4
	Not present	In planning	Early implementation/ available in a few settings	Mid-implementation/ moderate availability	Fully implemented/ available across all settings
<b>Processes for building capacity</b>					
Formal educational programs (based on established curricula)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Standard protocols for the most common conditions and symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mentoring by experienced professionals (including telephone consultation for less-experienced professionals caring for patients in the community)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
On-site/just-in-time training by experienced professionals specific to individual patients when they return to the community (home)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pediatric palliative care manual/guide developed or adapted for your community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Optional:</i> Tele-health or other technology for expanding availability of care where and when needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Optional:</i> Electronic medical record-sharing within and across institutions/ care settings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. **Outreach:** Indicate the number of outreach activities your network/coalition has undertaken over the last 6 months which targeted or involved each of the groups listed below. Outreach activities include: Lectures, presentations, meetings, and/or other contacts designed to: a) raise awareness about the need and about the services provided by the evolving network/coalition and care system; b) develop partnerships; c) identify children who need services; and/or d) garner financial support for the care system.

Outreach to:	0	1	2	3	4
	None	One	2 to 3	4 to 6	More than 6
Healthcare professionals (medical, mental health, allied therapists, bereavement care providers)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Healthcare trainees	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child life specialists/ Early intervention specialists/ Genetic counselors					
Families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
State/local governmental and social service agencies (e.g. Medicaid, United Way)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Healthcare organizational providers (hospitals, hospices, home care agencies, EMS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Schools and other key organizations serving children with special needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Faith communities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disease-specific organizations - local chapters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insurers (governmental or private)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vendors (e.g., DME, oxygen, supplies)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>